Distress in Response to and Perceived Usefulness of Trauma Research Interviews

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ABSTRACT. Because studying trauma often involves asking about upsetting experiences, it is important for researchers to study the effects of

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such interviews on research participants, particularly those who may be more vulnerable. In a study of psychiatric inpatients that included a structured interviews for PTSD and childhood physical and sexual assault experiences, participants rated how upsetting and how helpful or useful they found the interview. Of the 223 participants for whom we knew level of distress, 70% experienced relatively low levels of distress, and 51% found participation to be useful in some way. Level of upset was moderately to strongly related to levels of past trauma and current symptoms, while perceived usefulness was not significantly related to any experiences or symptoms.

KEYWORDS. Trauma, interviews, ethics, procedures, human subjects, experimentation

In the interest of protecting participants and respecting their autonomy, professional ethical codes require researchers to inform potential participants about factors that might influence willingness to participate in research. Typically this entails describing the research purposes and procedures, threats to confidentiality, risks of harm, costs, and potential benefits of participation (Sales & Folkman, 2000). Unfortunately, informed consent information about the costs and benefits of research participation is often based on opinions or assumptions, because little or nothing is known about the actual costs and benefits (Newman, Kaloupek, Keane, & Folstein, 1997). This is particularly problematic in research about traumatic events because many intuitively believe that it is distressing to disclose such information and that if participants knew in advance how distressed they might become, they would decline to participate.

Several recent studies have examined research participants' responses to trauma-related research. In general, acutely injured adults and children (Ruzek & Zatzick, 2000; Kassam-Adams & Newman, 2001), patients enrolled in an HMO (Newman, Walker, & Gefland, 1999), college students (Newman, Willard, Sinclair, & Kaloupek, 2001) and veterans (Parslow, Jorm, O'Toole, Marshall, & Grayson, 2000) endorse satisfaction with research participation and favorable cost-benefit ratios. In the HMO study that included childhood maltreatment interviews, most research participants found the overall experience to be positive or neutral

and very few said they would not have participated if they had known in advance what it would be like for them (Newman et al., 1999). Also, although severity of childhood maltreatment was related to becoming more upset than expected, most participants did not seem to regret their participation. Another study in which a PTSD interview was administered to a random sample of Vietnam veterans found participation sometimes caused short-term distress, but did not appear to cause any long-term harm to most participants (Parslow et al., 2000). While these studies provide useful information about the impact of trauma research on general population samples, more research is needed to understand the risks and potential benefits to more vulnerable populations, such as those receiving psychiatric treatment.

The current study evaluates how psychiatric inpatient research participants appraised the level of upset and potential usefulness of research participation experienced during trauma-focused research interviews. We hypothesized that the majority of the respondents would experience low or moderate levels of distress and would find participation useful. To better understand which participant characteristics might be related to reactions to the interviews, ratings for upset and usefulness were correlated with experience and symptom variables. Content of answers to free response questions about what aspects of research participation were perceived as distressing and/or useful were also analyzed.

METHOD

Participants

A group of 2,468 adults admitted to inpatient care at a large nonprofit psychiatric hospital were considered for recruitment in this study. We received replies to our contacts with admitting psychiatrists and psychologists in regard to 1,013 of these patients rapidly enough to permit contact before the patient was discharged. Because the average length of stay for patients was only seven days by the end of the first year of data collection, patients were often on the verge of discharge by the time their therapists received our request. Of therapists who replied, permission was given in regard to interviewing 884 patients (87%) and permission was refused in regard to 129 patients (13%). Typical reasons for refusal included medical instability or impaired mental capacity to give full informed consent (e.g., dementia, acute psychotic states, and profound mental retardation). Of the 884 patients we were given per-

mission to approach, 293 were discharged before we could contact them. Of the 591 potential participants who we were able to approach, 259 (43.8%) began the interview, 180 (30.5%) declined participation in the study, and 152 (25.7%) were discharged before they could be interviewed.

Measures

Upset in Response to the Interview. At the end of the interview, all participants were asked, "Did you find it upsetting to answer the interview questions?" Participants were then asked "how much" on a five point Likert scale (0 = not at all; 1 = a little bit; 2 = somewhat; 3 = very much; 4 = extremely). Participants were also asked, "What was upsetting about it?"

Perceived Usefulness of the Interview. Following the question about how upsetting the interview experience was, participants were asked, "Did you find it at all helpful or useful to you to answer the interview questions?" using the same five point Likert scale described above. Because many participants commented that it was not useful to them personally but that they hoped it would help others, we rephrased question for the final 108 participants to ask, "Did you find it at all helpful or useful to answer the interview questions?" Following this question, participants were asked either "How was it useful or helpful to you?" or "How was it useful or helpful?"

Trauma and Abuse Assessments. Frequency of childhood and adult traumatic events other than abuse were collected as part of the Structured Interview for PTSD (SI-PTSD). Physical abuse experiences were assessed with a structured interview based on the Physical Violence scale of the Conflict Tactics Scales (CTS) (Straus, 1979). Childhood sexual abuse experiences were assessed using an interview developed by Jacobson (Jacobson, 1989; Jacobson & Richardson, 1987). Physical abuse events categorized as violent were: being hit with an object, being kicked, bitten or hit with a fist, being burned, being beaten, or being threatened with a gun or knife. Sexual abuse events categorized as violent were: being forced to perform oral sex, attempted vaginal or anal intercourse, and vaginal or anal intercourse. Detailed descriptions and psychometrics of these interviews are reported in Carlson, Dalenberg, Armstrong, Daniels, Loewenstein, and Roth (2001).

PTSD Symptoms. The SI-PTSD was used to quantify PTSD symptoms. The SI-PTSD assesses and quantifies the DSM-IV diagnostic criteria for PTSD (Davidson, Kudler, & Smith, 1990; Davidson, Smith, &

Kudler, 1989). Interviewers assign participants a score on a five-point Likert scale (ranging from 0 to 4 with labels of not at all, mild, moderate, severe, and extremely severe) for each of 17 PTSD symptom criteria so that total SI-PTSD scores can range from 0 to 68. The SI-PTSD has been found to have good interrater reliability, good test-retest reliability, and good concurrent validity (Davidson et al., 1990; Davidson et al., 1989). It is important to note that SI-PTSD scores were available only for participants who reported one or more traumatic experiences on the screening item for the SI-PTSD.

Dissociation. The Dissociative Experiences Scale (DES) was used to quantify dissociative symptoms (Bernstein & Putnam, 1986). This 28-item, self-report measure inquires about experiences of amnesia, depersonalization, derealization, absorption, and imaginative involvement. Participants are asked to circle a number to show what percentage of the time each experience happens to them. Total scores on the scale are the average of the 28 items scores and can range from 0 to 100. The DES is a widely used measure of dissociation that has good reliability and validity (Carlson & Putnam, 1993).

Depression. The depression subscale from the Symptom Checklist-90-Revised (SCL-90-R) (Derogatis, 1983) was used to measure current level of depression. The SCL-90-R is a 90-item, self-report psychiatric rating scale that produces subscale scores for a variety of psychiatric symptoms. The scale has been used extensively in psychiatric research and has well-established psychometric properties (Derogatis, 1983). The depression subscale score is the average of subscale item scores and can range from 0 to 4.

Self-Destructiveness. The Structured Interview for Self Destructiveness (SI-SD) was used as a global measure of lifetime self-destructive behaviors. Interview questions inquire about disordered eating, self-mutilation, sexual impulsiveness, and suicidality. Based on participants' answers to interview questions and probes, interviewers assign a rating for each subscale that ranges from 0 to 3 (none, mild, moderate, severe). A total score for self-destructiveness is calculated by adding the four subscale scores and can range from 0 to 12. The SI-SD appears to have good reliability and validity (Carlson, unpublished data).

Aggression. Scores from measures of physical force against others and hostility were combined in this study to assess aggression in order to reflect both aggressive acts (physical force against others) and aggressive thoughts and impulses (hostility). A Physical Force form was used to assess a variety of uses of physical force against others during adulthood and childhood (excluding "fighting with other kids" during

childhood). This form was derived from the Physical Violence scale of the Conflict Tactics Scales (CTS; Straus, 1979). Participants were asked to report the frequency of each of the 11 physical force items from the Physical Violence scale of the CTS.

The total physical force score was calculated by summing frequencies of each type of aggressive behavior, with double weights assigned to those behaviors that Straus, Gelles, and Steinmetz (1980) defined as major assault (being kicked, bitten, or hit with a fist; burned; beaten up; or threatened with knife or gun). Applying unit weights was considered optimal in accordance with the "simple is better" principle espoused by Cohen (1990). An aggression score was calculated by adding standardized physical force scores to standardized scores from the SCL-90-R hostility subscale.

Procedures

To ensure that patients were stable enough to participate, admitting psychiatrists or psychologists were asked for approval to approach patients regarding participation. If obtained, the patient was approached by a trained, masters-level research technician who provided information about the study. In addition to information about confidentiality and their right to refuse participation or stop at any time, they were told that we would be asking about physical and sexual violence experiences. They were also told, "It is possible that some people will be upset by talking about some of the things that have happened to them in the past. But usually people do not get upset." Participants who agreed to participate completed the DES and SCL-90-R and were then individually administered a life events timeline, interview about childhood home environment, the SI-PTSD, physical and sexual abuse interviews, the aggression interview, the SI-SD, a structured interview for social support as a child, and the upset and usefulness questions (in that order).

A specific protocol was in place to respond to patients' distress during the interview. If the participant demonstrated any agitation or distress (e.g., crying), the interviewer inquired if the participant wanted to stop. This was repeated if necessary until the interview was stopped or completed. Interviews were terminated regardless of the participant's willingness to continue in cases of extreme distress. Also, the interview was immediately discontinued if the participant indicated a desire to stop for any reason. If an interview was stopped due to emotional upset, the participant's primary nurse was notified that the participant was dis-

tressed, although confidentiality of all information provided in the interview was maintained.

RESULTS

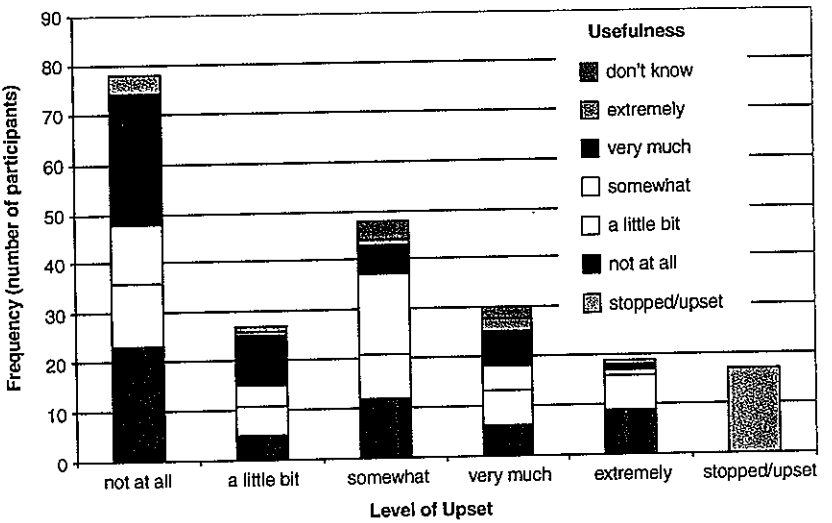
Of the 259 participants who began the interview, 206 completed the entire interview, 36 did not finish for various reasons other than being upset, and 17 did not finish because of being upset. Of the 17 who stopped because of being upset, 7 (2.7%) of those who began the interview stopped during the PTSD interview, and 10 (3.9%) of those who began stopped during or after questions about childhood events or abuse interviews. Of the 206 participants for whom reactions to the interview data was available, 56% were women and 44% were men; 36% were married, 30% were separated or divorced, and 34% were single or widowed; 80.6% of the sample was Caucasian, 16.5% were African-American and 2.9% were of another race. The average age of the participants was 37.7 (SD = 4.9). As measured by the Hollingshead Index (combines education level and occupation to estimate socioeconomic status with a range from 11 to 47), the mean score for socioeconomic status was 41 (SD = 17.4).

Figure 1 presents the frequencies of ratings of upset and usefulness for all participants who completed the interview and of interviews stopped because of being upset. Of 206 rating their level of upset, 49 said they were very much or extremely upset. Seventeen (17) stopped because they were upset before they formally rated their level of upset. Therefore, 66 of 223 (30%) for whom level of upset is known were highly distressed by answering interview questions. Of 199 participants who rated usefulness, 102 (51%) gave ratings of "somewhat," "very much," or "extremely." Level of upset and useful were significantly negatively correlated, $r\,(199) = -16$, $p < .02$.

Upset ratings were significantly correlated with symptoms of aggression ($r = .16$, $p < .02$) and with depression, dissociation, self-destructiveness, and PTSD (rs ranging from .39 to .56, for all $p < .001$). Upset ratings were also significantly correlated with violent physical abuse ($r = .31$), other physical abuse ($r = .36$), violent sexual abuse ($r = .57$), and other sexual abuse ($r = .52$) with $p < .001$ for all. Usefulness ratings were not significantly correlated with any experience or symptom variables.

Of the 206 participants who completed the interview, 126 (61%) gave a free response about upset and 140 (71%) gave a free response

FIGURE 1. Frequency of level of upset by level of usefulness.



about usefulness. Content analysis of free responses to questions about upset and usefulness was conducted by having two raters independently sort responses into predefined categories (see Table 1). The kappa coefficient for interrater agreement was .95 for the upset question and .90 for the usefulness question.

Typical responses to the upset question were: "Having to remember painful things" and "The fact that it brought up a lot of suppressed memories and stuff that I'd forgotten about over the years." Typical responses to the useful item were: "It puts things in perspective. When I look at my life, I can understand why I was so scared." and "I want to help stop this abuse. Maybe this project can help increase the understanding level. Even if only the researchers in the project understand better, it's worth it."

DISCUSSION

Overall, the majority (70%) of participants whose level of upset was known experienced low or moderate levels of distress when answering detailed interview questions about PTSD and trauma and about half (51%) found participation to be at least somewhat useful. On the other

TABLE 1. Categories for Type of Upset and Perceived Benefits

Overall Category	Definition	Percent Who Endorsed
Why Upsetting?	Remembering/reliving past, recognizing memory gaps	46.4
	Upset by detailed nature of the questions	16.0
	Led to painful insights	11.2
	Upsetting to talk/tell about trauma	7.2
	Evoked negative emotions	7.2
	Caused dissociation	4.8
	Embarrassing or shameful	3.2
	Other	4.0
How Useful?	Led to new insights	35.6
	Helped to tell/talk to someone	16.4
	Helped remember past better	11.6
	It could be helpful to others	10.3
	Felt like a relief/carthasis	7.5
	Will be helpful in own therapy	6.2
	Remembering positive aspects of life	5.5
	Other	6.8

hand, 17 (6.6%) of those who began the interviews did not finish because of being upset, and another 49 of the 206 (24%) who completed interviews rated themselves as very much or extremely upset by answering the questions. Of the 49 who rated their upset as high, 18 (37%) found the experience at least "somewhat" useful. Correlations between levels of upset and other variables indicate that being upset by participation was moderately to strongly related to level of past trauma and to levels of current symptoms. Collectively, these findings provide important information about the risks and benefits of participation in trauma-related interviews for those with the highest level of psychiatric disturbance and about participant characteristics that are associated with increased risk of distress.

The finding that ratings for usefulness were not significantly related to any experience or symptom variable indicates that how useful participants found the interviews was not related to their own level of trauma experiences or symptoms. The analyses of free responses shed some light on this issue and reveal an interesting paradox: the most prominent reason given for why the interview was upsetting (remembering the past) was also the means of achieving the most prominently reported benefit (led to new insights). In some ways, then, what is upsetting about participating in trauma interviews may be inextricably entwined

with what is useful about participating. Interestingly, this is the same paradox that often holds for psychotherapy in general: discussing emotionally painful material is what is most likely to lead to therapeutic gain. However, unlike psychotherapy, this research required that individuals recall the events with no expectation or guarantee that the experience will be one of personal benefit.

With respect to research practice, these results suggest that it may be wise as part of the consent process to emphasize that research participation may result in experiencing distressing emotions. Furthermore, these results suggest that it may be useful to use a standard tool to assess participants' responses to clinical research protocol, so that the research team can respond to any distress related to participation. Direct empirical assessment of participant reactions also is consistent with recent recommendations to include "consumer" perspectives in the creation and evaluation of research proposals (Heymann, 1995; National Bioethics Advisory Commission, 1998).

It is important to note that these results probably represent a "worst case scenario" in terms of the number of participants who were distressed by participation and their level of distress. We conclude this based on findings from other studies that psychiatric inpatients generally have higher levels of trauma exposure and PTSD than other treatment samples or than general population samples. While sampling limitations prevent generalization of these findings to all psychiatric inpatients, we believe the participants do represent those psychiatric inpatients who participate in studies of this nature. This is because any similar studies are likely to use very similar procedures to screen patients for participation so that only those who are psychiatrically stable, available, and willing to participate will be interviewed. Of the 259 persons who fit this description and began interviews, we had information about the level of upset of 223 (86%) and information about perceived usefulness for 199 (77%).

A limitation of this study is that we assessed immediate level of upset, but did not assess if this level of upset was disabling, an intensification of existing symptoms, or evoked existing symptoms that survivors confront as part of their daily lives. Furthermore, one significant limitation of this study is that we assessed only immediate distress, not persistent distress, which is arguably more important. While some might consider it a limitation of this study that we did not ask participants to weigh the relative costs and benefits of participation, it would have been difficult for participants to do so because–while they were hopeful about the eventual benefits of the study to others–they were unable to

gauge them. Future studies might ask participants whether they feel the costs to them were worth the benefits to themselves or others, assuming that the findings did benefit others. Further studies might also ask participants to identify procedural factors that might help minimize their distress. Finally, it may be useful to develop some way of assessing and understanding what leads individuals to choose *not* to participate in a particular research study.

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